Coping is excellent in Swiss Children with inflammatory bowel disease: Results from the Swiss IBD cohort study

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Abstract: BACKGROUND: Inflammatory bowel disease (IBD) starting during childhood has been assumed to impair quality of life (QoL) of affected children. As this aspect is crucial for further personality development, the health-related quality of life (HRQOL) was assessed in a Swiss nationwide cohort to obtain detailed information on the fields of impairment. METHODS: Data were prospectively acquired from pediatric patients included in the Swiss IBD Cohort Study. IBD activity was evaluated by PCDAI and PUCAI. The age adapted KIDSCREEN questionnaire was evaluated for 110 children with IBD (64 with Crohn's disease 46 with ulcerative colitis). Data were analyzed with respect to established reference values of healthy controls. RESULTS: In the KIDSCREEN index a moderate impairment was only found for physical wellbeing due to disease activity. In contrast, mental well-being and social support were even better as compared to control values. A subgroup analysis revealed that this observation was restricted to the children in the German speaking part of Switzerland, whereas there was no difference compared to controls in the French part of Switzerland. Furthermore, autonomy and school variables were significantly higher in the IBD patients as compared to controls. CONCLUSIONS: The social support for children with IBD is excellent in this cohort. Only physical well-being was impaired due to disease activity, whereas all other KIDSCREEN parameters were better as compared to controls. This indicates that effective coping and support strategies may be able to compensate the burden of disease in pediatric IBD patients.

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Coping is excellent in Swiss Children with Inflammatory Bowel Disease: results from the Swiss IBD Cohort Study

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What is known about this topic?

- Inflammatory bowel disease (IBD) impacts the quality of life (QoL) in pediatric patients.
- Pediatric IBD patients may have difficulties with school, inability to participate in physical activities decreased social competences.
- Pediatric patients with IBD are at risk for depression, anxiety, social isolation, and altered self-image, which can negatively affect health-related quality of life (HRQOL)

What this study adds

- In the KIDSCREEN index only a moderate impairment of children with IBD found for physical well-being in the Swiss cohort study.
- Mental well-being and social support were not different or even better than control values, indicating that depression and emotional impairment were not more abundant in paediatric IBD patients of this cohort.
- Autonomy and school variables were significantly higher in the paediatric IBD patients in this Swiss cohort.

Contributorship

Daniela Rogler – manuscript concept, data collection, statistical analysis, writing of manuscript (main author)
Nicolas Fournier – data retrieval from database, statistical analysis, writing of manuscript
Valérie Pittet - national study coordinator, data analysis, writing of manuscript
Patrick Bühr – patient recruitment, writing of manuscript
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The authors report no competing interest.

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Abstract:

Background: Inflammatory bowel disease (IBD) starting during childhood has been assumed to impair quality of life (QoL) of affected children. As this aspect is crucial for further personality development, the health-related quality of life (HRQOL) was assessed in a Swiss nationwide cohort to obtain detailed information on the fields of impairment.

Methods: Data were prospectively acquired from paediatric patients included in the Swiss IBD Cohort Study. IBD activity was evaluated by PCDAI and PUCAI. The age adapted KIDSCREEN questionnaire was evaluated for 110 children with IBD (64 with Crohn's disease 46 with ulcerative colitis). Data were analyzed with respect to established reference values of healthy controls.

Results: In the KIDSCREEN index a moderate impairment was only found for physical wellbeing due to disease activity. In contrast, mental well-being and social support were even better as compared to control values. A subgroup analysis revealed that this observation was restricted to the children in the German speaking part of Switzerland, whereas there was no difference compared to controls in the French part of Switzerland. Furthermore, autonomy and school variables were significantly higher in the IBD patients as compared to controls.

Conclusions: The social support for children with IBD is excellent in this cohort. Only physical well-being was impaired due to disease activity, whereas all other KIDSCREEN parameters were better as compared to controls. This indicates that effective coping and support strategies may be able to compensate the burden of disease in paediatric IBD patients.

Keywords: paediatric inflammatory bowel disease; mental well-being; physical well-being; coping; social support.

Introduction

Inflammatory bowel diseases (IBD), which include Crohn's disease (CD) and ulcerative colitis (UC) as well as unclassified IBD, are chronic and sometimes disabling diseases with unpredictable courses and difficult treatment. Epidemiological studies report high and rising incidence of childhood IBD in Western and Northern Europe, in North America and in Asia[1-10].

Therapy for IBD has rapidly evolved during recent years with the introduction of novel therapies and treatments. Some of these new treatments are expensive and their benefit/risk ratio has to be carefully evaluated. On the other hand, the impact of those new therapies on patient quality of life (QoL) is often considerable. Paediatric IBD patients are affected by a number of problems that are not restricted to the gastrointestinal tract[9, 11-13]. When these chronic diseases manifest during childhood or adolescence, which is obviously a critical developmental period, the transition to adulthood can be impaired by physical but also by psychological factors[14]. Paediatric patients with severe IBD, particularly CD, frequently suffer from malnutrition, growth failure and pubertal delay at the time of diagnosis[15-18]. Furthermore, self-reported difficulties with school absenteeism, inability to participate in physical activities [19, 20] and parental-reported decreased social competences[21-23] have been reported.

It is known that - similar to other chronic diseases of childhood and adolescence - patients with IBD are at risk for depression, anxiety, social isolation, and altered self-image, which can negatively affect health-related quality of life (HRQOL)[14, 24-27]. Identifying patients with impaired quality of life is of importance, as it may change treatment strategies[14, 27].

In 2006 a nationwide cohort study on patients with IBD in Switzerland, the Swiss IBD Cohort Study (SIBDCS), was initiated [28]. The general aim of the SIBDCS is to provide the Swiss and international scientific, public health and medical community information on a disease-oriented prospective cohort of inflammatory bowel disease patients. Data from the Swiss IBD cohort (SIBDC) represent up-to date epidemiological data (e.g. prevalence, incidence, clinical course of IBD) [28]. In the paediatric sub-cohort, the Swiss Paediatric IBD cohort study (SPIBDCS), quality of life and psychological adjustment has been evaluated by the KIDSCREEN questionnaire. So far it was not clear how this score is associated with characteristics of the disease and demographic variables. The purpose of this project was to examine medical, individual and demographic determinants of health-related quality of life in children and adolescents with IBD. We hypothesized that in a well-functioning health system the impact of IBD on HRQoL is limited and coping can support an almost normal mental well-being in paediatric IBD patients.

To challenge our hypothesis the KIDSCREEN results of 110 children in the cohort were correlated with medical factors of potential impact such as disease activity (PCDAI, PUCAI), surgery, complications, and disease duration. In addition, individual factors of the patient (such as age, gender, education, and migratory background) were analyzed.

Materials and Methods

Patients

Since 2006, 2530 adult and pediatric IBD patients from all regions of Switzerland have been included into the nationwide Swiss IBD Cohort Study that is supported by the Swiss National Science Foundation (SNF) and approved by the local ethics committees[28]. Informed consent was obtained from parents and/or patients. At the time of inclusion, patients underwent a thorough clinical and laboratory assessment including calculation of clinical IBD disease activity scores (including PCDAI and PUCAI for paediatric patients). Data acquisition focused on clinical, socio-economic and psychosocial data. 110 paediatric patients were available for analysis. Data quality was assessed by internal review.

Definitions

We retrieved data from the registry including demographic items (age and level of education at diagnosis, parental age, level of education and economical status at diagnosis, siblings and their age and level of education at diagnosis, as well as the medical, social and migratory family history), IBD disease factors (disease extension, inflammatory activity, complications, current medication, past therapeutic interventions, growth and puberty, co-morbidity) as well as data from these activity indices:

The Paediatric Crohn's Disease Activity Index (PCDAI) is a reliable and valid 8-item measure designed to assess disease activity in paediatric patients with CD. It takes into account patient history and the following laboratory data: complete blood count (CBC), erythrocyte sedimentation rate (ESR), and albumin. Scores range from 0–

100, with ≤10 indicating inactive disease, 11–30 indicating mild disease, and >30 indicating moderate-to severe disease[29, 30].

The Paediatric Ulcerative Colitis Activity Index (PUCAI) is a validated, non-invasive, 6-item measure of disease activity with established cut-off values for remission (<10 points), mild (10–34 points), moderate (35–64 points), and severe disease (65–85 points). The index takes into account stool frequency, stool consistency, presence of bloody stools, nocturnal stools, abdominal pain, and patient activity level[31].

Questionnaires

The KIDSCREEN-27 is a Quality of life Questionnaire consisting of 27 items measuring physical well-being, psychological well-being, autonomy and parent relations, peers and social support, and school environment. The KIDSCREEN-27 was developed as a shorter version of the KIDSCREEN-52 with good psychometric properties[32]. Each of the 27 items is rated as being not true (0), somewhat true (1), balanced (2), rather true (3) or certainly true (4). Interscale correlation range from 0.36 to 0.59 (0.33–0.57) for the self-report (proxy report)[33, 34]. The KIDSCREEN has been validatet in a large study involving 3988 children and 2526 child-proxy pairs in seven European countries (Austria, Switzerland, Germany, Spain, France, United Kingdom, and the Netherlands) [32].

Sociodemographic information

Sociodemographic information included age and gender of the child, language of the survey (French speaking part of Switzerland versus German speaking part), migration status of the child, education, parental education and socioeconomic status.

Statistical Analysis

Clinical data were retrieved from the data centre of the SIBDCS at the University of Lausanne. The data were entered into a database (Access 2000, Microsoft Switzerland Ltd Liab. Co, 8304 Wallisellen Switzerland). All statistical examinations were performed with the STATA statistical software (STATA version 12.1, StataCorp, College Station TX, USA).

Continuous variables distribution was analyzed using Normal-QQ-plots. Gaussian continuous variables are presented as the mean ± the standard deviation (SD), while non-Gaussian as the median and interquartile range (IQR). Categorical variables are given as counts and proportions. Differences between two independent groups with regard to Gaussian continuous variables are quantified with the two-sample Student's t-test, or with the Mann–Whitney–Wilcoxon test in case of non-Gaussian distribution. Differences between more than two independent groups with regard to Gaussian variables are quantified with an analysis of variance (ANOVA), or with the Kruskall-Wallis test in case of non-Gaussian data. Categorical variables are compared between groups using the chi-squared ($\chi 2$) test or Fisher's exact test for small samples.

The strength of association between normally distributed continuous variables was measured using Pearson's correlation coefficient or Spearman's correlation coefficient when the variables presented a non-Gaussian distribution. A p-value < 0.05 was considered statistically significant.

Results

Clinical Characteristics of the Study Population

143 paediatric patients with IBD have been included into the SIBDCS between 2007 and 2012 of which 110 could be analysed for this study. In the analysed group 64 had CD and 46 UC. The characteristics of the whole study population are given in **table 1**. Thirty-one (37.3%) of the children in the CD group and 33 (55.0%) in the UC group were female (p = 0.036). The median age of the paediatric CD and UC patients was comparable: median CD: 14 years (IQR 12 – 15) and 13.5 (11 – 15) years for UC, respectively (p = 0.192) (see **table 1**). 13.3% of CD patients had ileal involvement only (L1 according to the Montreal classification), 13.3% had only colonic involvement (L2), 45.8% had ileocoecal inflammation (L3) and 22.9% had upper GI involvement (L4) (see **table 1**).

With data collected in SIBDCS enrolment questionnaire, we are not be able to make the distinction L1/L4a/L4b as in the Paris classification as the study had been initiated in 2006 before the Paris classification was published in November 2010. Nevertheless, it is possible for further give details on report the disease behaviour for CD. B1 disease behaviour (nonstricturing, nonpenetrating) was found 63 (75.9%), B2 (stricturing only) in 7 (8.4%), B3 (penetrating only) in 10 (12.1%) and B2B3 (both stricturing and penetrating) in 3 (3.6%) of our patients **(table 1).** Perianal disease was absent in 58 (69.9%) and present in 25 (30.1%) of the patients.

In the UC population, 3.3% had proctitis only, 15.0% had left sided colitis and 76.7% had pancolitis. This is in accordance with other reports indicating a higher percentage of pancolitis in paediatric UC patients [35-39]. Active disease at time of enrolment visit (PCDAI > 150 or PUCAI ≥ 10) was noted in 39.5% of patients with CD and

37.3% of patients with UC, respectively. Active disease at time of KIDSCREEN interview was noted in 35.7% of patients with CD and 28.0% of patients with UC. It needs to be mentioned that enrolment questionnaire (physician visit) and KIDSCREEN interview were not necessarily carried out at the same time point. However, 81/110 KIDSCREEN interview were made within +/- 10 days of enrolment visit. The medical therapy of all pediatric CD and UC patients at the time of the survey is summarized in **table 2**. It indicates that 70.0% patients with UC and 24.1% of patients with CD were currently treated with 5-ASA (p-value < 0.001). We also observed a small statistically not significant difference for Infliximab treatment (19.3% in CD vs 8.3% in UC, p-value = 0.068) and for no current therapy at all (3.6% in CD vs 11.7% in UC; p-value = 0.062). Use of adalimumab treatment was very rare, as well as combination therapies involving immunosuppressants and anti-TNF agents.

HRQoL in the total sample

In general, children and adolescents with IBD reported a lower score for physical well being as compared to their healthy peers (**table 3**). However, the difference was not statistically significant. We did not observe a difference between patients with CD and UC. Furthermore, physical well-being seemed not to be affected by history of surgery (47.8 ± 12.1 vs 47.7 ± 10.2, p-value = 0.973). In addition, we could not find a statistically significant difference between CD patients with purely inflammatory behavior (B1 only) and CD patients with more complicated behavior (B2 and/or B3) for the mentioned parameters. However, there was a clear trend for a better score (p = 0.069) for physical well-being in the children with B1 disease behaviour. The same was found for the comparison between CD Patients with and without perianal disease. Whereas in general scores were very similar there was a trend for a better

score in CD patients without perianal disease for physical well-being (p = 0.099) **(table 3).** It is noteworthy that mental well-being was not affected at all by the disease behaviour. Surprisingly also no difference between patients with active disease and patients in remission was detected.

In contrast, surprisingly the mental well-being was found to be significantly higher in the IBD patients as compared to healthy controls (IBD patients: 53.4 ± 10.7 vs controls: 50.0 ± 10.0, p-value = 0.001). A significant difference could also be found with respect to parents/autonomy (54.4 ± 11.7 vs 50.00 ± 10.00, p-value < 0.001), which was higher in paediatric IBD patients as compared to healthy controls. We found no difference between CD and UC patients with respect to these parameters. While parents/autonomy scores were not different between patients free-of-surgery and patients with a past surgical procedure, we could observe significant difference for the mental well-being score (no surgery: 52.7 ± 10.5 vs surgery 59.6 ± 11.4, p-value = 0.043).

For social support in the total cohort, a statistically significant difference again could be found between IBD patients and controls (54.8 ± 10.6 vs 50.0 ± 10.0, p-value < 0.001). There was no difference between CD and UC patients, as well as surgery-free patients vs patients with a positive surgery history.

Similar to what we found for parents' support and social support the values for self-evaluation of school performance were even higher in the IBD cohort as compared to healthy children (53.3 ± 10.4 vs 50.00 ± 10.00, p-value = 0.001). Again this did not differ between CD vs UC patients. The history of surgery had no impact on this finding.

Disease duration was not found to be a statistically significant factor for any of the KIDSCREEN subscores. We observed a negative association of disease duration

with physical well-being and social support, but a positive association with the three other subscores, especially mental well-being (Spearman's rho: 0.133, p-value=0.168)

Socioeconomic status and HRQoL

Socioeconomic status, education of the parents and migratory background were analysed. Social supports are known to correlate with these factors. Therefore, we further analyzed the following socioeconomic factors: mother formation (low vs high), father formation (low vs high), mother's country of birth (Switzerland vs other), father's country of birth (Switzerland vs other), and parent's country of country (both Switzerland vs one Switzerland vs both other). The vast majority of children were born in Switzerland, and therefore a comparison for the child birth country was not possible. We defined higher education as having university, "technicum", higher professional school. For mothers lower education was reported in 50 cases (66.7%) and higherin 25 (33.3%), missing = 40. For fathers the numbers were: Low = 36 (57.1%), high = 27 (42.9%), missing = 52. The results are given in table 4. Only the difference between "No parents born in Switzerland" and "Two parents born in Switzrtland" turned out to be statistically significant at 1.7% level (Bonferroni correction).

HRQoL in paediatric IBD across the French and German part of Switzerland

Surprisingly we found a difference for the HRQoL variables between the French and German speaking part of Switzerland (**table 5**). Whereas there was no difference as compared to healthy children for physical well-being in the German speaking IBD cohort (49.6 ± 11.7, p-value = 0.750 vs control) there was a clear impairment in the

French speaking part of Switzerland (40.1 ± 10.0, p-value = < 0.001 vs control). We observed that this finding was independent of the diagnosis, detecting the same kind of differences when stratifying by disease type, except for French speaking UC patients (42.39 ± 10.11, p-value = 0.093), where a sample size of only 7 could play a role.

Whereas the scores for mental well-being were even higher as compared to healthy subjects in the German speaking patient group (54.5 ± 10.8, p-value< 0.001 vs control) there was a non-significant reduction in mental well-being in the French speaking patient group (48.8 ± 9.4, p-value = 0.576 vs control). The same trend was found for parents/autonomy (German speaking patient cohort: 55.6 ± 11.0, p < 0.001vs control; French speaking patient cohort: 49.4 ± 13.4, p-value = 0.838 vs control) and for social support/peers (German speaking patient cohort: 55.9 ± 9.1, p-value < 0.001vs control; French speaking patient cohort: 49.8 ± 15.0, p-value= 0.950 vs control). For school performance better values were recorded in both sub-cohorts with a significant difference only in the German speaking individuals (German speaking patient cohort: 53.7 ± 10.0, p-value < 0.001vs control; French speaking patient cohort: 51.2 ± 12.0, p-value = 0.671 vs control). Again, we found similar differences when taking into account disease type separately, with the only exception of school environment for German speaking UC patients (52.0 ± 8.7, p-value = 0.162).

Age- and gender-specific HRQoLin paediatric IBD

Gender-specific results are shown in **table 6** and **figure 1**. Boys with IBD presented a lower score for physical well-being than the control population (46.8 ± 10.7 vs 50.0 ± 10.0, p-value = 0.022), and the four other scores were higher than for the control population, however not statistically significant for mental well-being and school

environment. Girls with IBD presented a similar pattern, but physical well-being was not found to differ significantly from the control population (47.8 ± 12.6 vs 50.0 ± 10.0, p-value = 0.224). Nevertheless, when comparing boys with IBD to girls with IBD, we found no statistical difference. This finding was independent of the disease type.

Differences between children (< 12 years old), young adolescents (between 12 and 14 years old) and old adolescents (> 14 years old) are shown in **figure 2** (for discrimination of young versus older adolescents see [14, 40,Cotton, 2009 #1019, 41]). Children systematically report a lower HRQoL as compared to young and old adolescents; however the differences are not statistically significant. For children, no statistical difference was found among the five subscores compared to control group. On the contrary, young and old teenagers showed significantly higher mental, parental, social and school scores compared to control group, but physical well being was not statistically different from the control group, although lower in mean.

Discussion

The present paper demonstrates in a large cohort of paediatric IBD patients the impact of the disease on HRQoL. To our knowledge, this is one of the first studies investigating the impact on HRQoL with a generic and internationally valid HRQoL instrument. The study provided several surprising results. First, in the KIDSCREEN index an only moderate impairment of children with IBD as compared to healthy, age matched controls was found for physical well-being. This impairment of physical well-being may obviously be caused by the activity of the intestinal inflammation and the consecutive symptoms of the disease. Second, mental well-being and social support were not different or even better than control values, indicating that in contrast to other reports depression and emotional impairment are not more abundant in paediatric IBD patients of this cohort. Third, autonomy and school variables were significantly higher in the paediatric IBD patients in this Swiss cohort.

The impact of IBD on the physical well-being appeared to be different in the French and German speaking part of Switzerland. No simple factors could be identified that would easily explain this observed difference. However, even in the French speaking part of our cohort no clearly negative impact of IBD on psychological parameters was observed. Interestingly in an evaluation of the KIDSCREEN between different countries using the self-report version, the highest scores were observed in the Netherlands (53.9) and Austria (53.1) and the lowest values in France (46.8) and Poland (46.8)[42]. A general trend to a lower score in the French population may well contribute to our findings. It would explain why the scores from the French speaking paediatric IBD patients are lower (as compared to the average healthy control score). It would further support the concept that mental and social HRQoL scores are not impaired in the paediatric IBD patients in our cohort.

Previous evaluations of the KIDSCREEN score have shown that children aged 8–11 score higher than adolescents aged 12–18 on the self-report and parent-report version[42]. In addition, girls had a trend to slightly lower scores, which was only significant in the 8 – 11 years age-group. In our cohort we could not find any significant gender difference in any age group. In contrast the numbers were even higher (but not significant) for all parameters among the female patients (**figure 1**).

In contrast to previous studies we could not find an impaired mental well-being in our patients. Engstrom et al. had reported that parents of paediatric IBD patients had significantly lower scores on a social support scale[43]. The mental health of the children with IBD correlated with the social support[43]. On the other hand Engstrom already found that HRQoL in paediatric IBD patients is not only dependent on the course of the intestinal inflammation but also on the psychological and social support and situation [44]. With respect to those findings we conclude from our data that good social support may enable paediatric IBD patients to completely cope with their symptoms. This further underlines the importance of social support and good coping strategies. There was only a minor impact of the socioeconomic background of the patients.

Our results with respect to the impact of surgery on HRQoL also are in contrast to other reports: Casellas and co-workers compared 29 CD patients in remission with previous bowel resections to 42 clinically active CD patients and 48 patients with medically induced remission with respect to HRQoL measured by Inflammatory Bowel Disease Questionnaire (IBDQ), the Psychological General Well Being Index (PGWBI), and the EuroQol. They found that both operated and non-operated inactive CD patients had lower HRQOL scores than controls[45]. Emotional, social, or functional dimensions did not differ significantly between operated and non-operated

inactive CD patients[45]. They conclude that HRQoL is impaired in active CD, and improves during remission irrespective of whether it had been achieved medically or surgically[45]. While we also did not detect significant differences for parents/autonomy scores between free-of-surgery patients and patients with a past surgical procedure, the patients that had undergone surgery had a significantly better mental well-being score.

In line with our findings are studies reporting that steroid exposure, hospitalizations, and time from IBD diagnosis do not significantly impact on HRQoL in paediatric IBD[46].

Our study has strengths and limitations. One strength is the cohort design evaluating the health related quality of life in a large proportion of paediatric Swiss IBD patients. The quality of the data is robust. A possible limitation may be that a selection bias occurred as mainly patients from representative university hospitals and less from private practices have been included. However, it can be assumed that paediatric patients treated in private practice have less health impairments and that a predominance of clinic patients may – if at all – introduce a bias towards more severe disease and consecutively more impairment of the health related quality of life. In addition only few children with IBD are cared for in private practice contrary to the adult patient with IBD. Another limitation may be the instrument used here, the KIDSCREEN index. While most children deny in questionnaires or interviews that IBD interferes with their lives, with persistent questioning many admit frustration and anger about their IBD symptoms and treatment[14, 47]. Further, the question, whether a statistical significant difference in the KIDSCREEN represents a clinically important difference is difficult to answer. Indeed many of the scores were quite close.

In conclusion, our cohort study demonstrates that mental well-being, social support as well as school performance are excellent in the paediatric Swiss IBD cohort. HRQoL does not necessarily need to be impaired in children with IBD as long as coping strategies are effective.

Tables

Table 1 Clinical characteristics of the whole cohort of paediatric patients of the SIBDC. Active Disease was defined as PCDAI > 150 for CD and PUCAI >= 10 for UC.

	CD	UC	p-Value
Number of patients	**83**	**60**	**-**
Female	**31 (37.3%)**	**33 (55.0%)**	**0.036**

Age: median (IQR)	**14 (12 – 15)**	**13.5 (11 – 15)**	**0.192**
Age at diagnosis: median (IQR)	**11.9 (10 – 13.9)**	**10.8 (7.1 – 12.7)**	**0.011**
Disease duration (years): median (IQR)	**1.25 (0.7 – 2.2)**	**2.1 (1.3 – 3.5)**	**0.002**
CD location : **L1 (Ileal)** **L2 (Colonic)** **L3 (Ileo-colonic)** **L1 + L4** **L2 + L4** **L3 + L4** **Unknown or unclear**	**-** **11 (13.3%)** **11 (13.3%)** **38 (45.8%)** **1 (1.2%)** **5 (6.0%)** **13 (15.7%)** **4 (4.8%)**	**-**	
CD behaviour: **B1 (nonstricturing, nonpenetrating)** **B2 (stricturing only)** **B3 (penetrating only):** **B2B3 (both stricturing and penetrating)**	 **63 (75.9%)** **7 (8.4%)** **10 (12.1%)** **3 (3.6%)**		
Perianal disease:	**No = 58 (69.9%)** **Yes = 25 (30.1%)**		
UC location **Proctitis** **Left sided colitis** **Pancolitis** **Unknown or unclear**	**-**	 **2 (3.3%)** **9 (15.0%)** **46 (76.7%)** **3 (5.0%)**	
PCDAI: median (IQR; range)	**10 (5-17.5; 0-40)**	**-**	
PUCAI: median (IQR; range)	**-**	**5, (IQR 0-15, 0-60)**	
Active disease	**17 (39.5%)** **(40 missing)**	**22 (37.3%)** **(1 missing)**	**0.817**
CD surgery	**11 (13.3%)**	**-**	**-**
UC surgery	**-**	**1 (1.7%)**	**-**

Table 2. Current medication of the pediatric IBD patients

Medication	CD	UC	p-Value
None	3 (3.6%)	7 (11.7%)	0.062
5-aminosalicylates	20 (24.1%)	42 (70.0%)	< 0.001
Azathioprine/6-MP	50 (60.2%)	29 (48.3%)	0.158
Infliximab (monotherapy)	16 (19.3%)	5 (8.3%)	0.068
Adalimumab (monotherapy)	2 (2.4%)	1 (1.7%)	1.000
Azathioprine+infliximab	2 (2.4%)	1 (1.7%)	1.000
Azathioprine+adalimumab	2 (2.4%)	0 (0.0%)	0.510
Methotrexate	10 (12.1%)	7 (11.7%)	0.945
Antibiotics	2 (2.4%)	0 (0.0%)	0.510
Others	21 (25.3%)	10 (16.7%)	0.216

Table 3. Values of the KIDSCREEN self report T-scores

	IBD Patients				
	Nb	Mean	Std dev.	t-value*	p-value*
Total Cohort					
Physical well-being	110	47.8	11.9	-1.943	0.054
Mental well-being	110	53.4	10.7	3.323	0.001
Parents/autonomy	110	54.4	11.7	3.976	< 0.001
Social support/peers	108	54.8	10.6	4.761	< 0.001
School	107	53.3	10.4	3.285	0.001

*Ho: mean = 50 (control)

	CD Patients			UC Patients			
	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value**
Physical well-being	64	47.3	12.2	46	48.5	11.7	0.594
Mental well-being	64	52.7	10.7	46	54.4	10.8	0.420
Parents/autonomy	64	54.8	11.8	46	53.9	11.6	0.706
Social support/peers	63	54.3	11.2	45	55.6	9.7	0.499
School	62	54.0	10.8	45	52.3	9.7	0.424

**Two-sided

	Patients without surgery history			Patients with surgery history			
	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value**
Physical well-being	99	47.8	12.1	11	47.7	10.2	0.973
Mental well-being	99	52.7	10.5	11	59.6	11.4	0.043
Parents/autonomy	99	54.2	11.6	11	56.3	13.0	0.569
Social support/peers	97	54.5	10.9	11	57.6	6.3	0.368
School	97	53.3	10.4	10	53.5	10.4	0.935

**Two-sided

	CD Patients with	CD Patients with	

	purely inflammatory behavior (B1 only)			more complicated behavior (B2 and/or B3)			
	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value**
Physical well-being	48	48.9	12.5	16	42.5	10.2	0.069
Mental well-being	48	52.1	10.6	16	54.4	11.0	0.466
Parents/autonomy	48	55.4	11.4	16	52.9	13.2	0.460
Social support/peers	48	54.6	11.8	15	53.2	9.3	0.673
School	48	54.1	10.8	14	53.6	11.3	0.872

**: Two-sided

Comparison of perianal disease vs no perianal disease:

	CD Patients with no perianal disease			CD Patients with perianal disease			
	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value**
Physical well-being	46	45.7	12.6	18	51.3	10.3	0.099
Mental well-being	46	51.7	11.3	18	55.1	8.7	0.261
Parents/autonomy	46	54.8	11.3	18	54.8	13.4	0.997
Social support/peers	45	54.2	11.6	18	54.5	10.4	0.928
School	44	53.2	9.6	18	55.8	13.5	0.408

**: Two-sided

	Patients in remission			Patients with active disease			
	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value**
Physical well-being	34	49.6	10.7	16	46.6	15.5	0.431
Mental well-being	34	52.6	10.4	16	53.9	14.4	0.712
Parents/autonomy	34	54.4	11.7	16	54.9	9.0	0.888
Social support/peers	34	53.8	9.7	15	52.1	13.6	0.612
School	34	55.1	10.4	15	52.6	10.6	0.456

**: Two-sided

	Correlation with Disease Duration		
	Nb	Spearman's rho	p-value**

Physical well-being	109	-0.007	0.941
Mental well-being	109	0.133	0.168
Parents/autonomy	109	0.084	0.381
Social support/peers	107	-0.111	0.251
School	106	0.059	0.544

**Two-sided

Table 4: Socioeconomic status ans HRQoL

Mother formation:

	Mother with no higher education			**Mother with higher education**			
	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value**
Physical well-being	50	49.8	11.6	25	42.4	9.7	0.008
Mental well-being	50	54.3	9.6	25	50.4	11.6	0.125
Parents/autonomy	50	54.5	12.5	25	52.7	11.6	0.541
Social support/peers	50	55.1	10.4	23	50.9	9.8	0.113
School	50	53.4	10.3	22	53.0	9.1	0.871

**: Two-sided

Father formation

	Father with no higher education			**Father with higher education**			
	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value**
Physical well-being	36	49.4	12.2	27	42.8	10.2	0.025
Mental well-being	36	53.6	10.5	27	50.2	9.7	0.190
Parents/autonomy	36	54.5	13.3	27	51.5	11.3	0.356
Social support/peers	36	53.6	11.5	25	52.8	10.5	0.778
School	36	53.0	10.9	24	52.3	8.5	0.781

**: Two-sided

Mother's country of birth:

	Mother not born in Switzerland			**Mother born in Switzerland**			
	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value**
Physical well-being	16	43.1	13.0	63	49.7	12.0	0.054
Mental well-being	16	50.6	11.5	63	54.4	10.6	0.206
Parents/autonomy	16	54.3	12.3	63	54.7	12.3	0.901
Social support/peers	15	52.7	11.0	62	54.5	10.3	0.545
School	14	57.8	11.3	62	52.3	9.8	0.070

**: Two-sided

Father's country of birth:

	Father not born in Switzerland	**Father born in Switzerland**	

	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value**
Physical well-being	24	44.6	12.7	55	50.1	11.9	0.066
Mental well-being	24	51.2	12.9	55	54.6	9.8	0.201
Parents/autonomy	24	54.4	13.7	55	54.7	11.7	0.921
Social support/peers	22	54.4	12.2	55	54.0	9.8	0.864
School	21	53.8	11.3	55	53.2	9.9	0.804

**: Two-sided

	No parent born in Switzerland			**One of the two parents born in Switzerland**			**Both parents born in Switzerland**			
	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value***
Physical well-being	12	40.2	12.7	15	50.2	11.5	51	45.8	10.2	0.039
Mental well-being	12	48.5	11.4	15	55.5	13.2	51	54.5	9.8	0.184
Parents/autonomy	12	53.5	13.9	15	56.4	12.2	51	54.5	12.0	0.818
Social support/peers	11	53.2	12.0	14	54.7	12.1	51	54.2	9.9	0.938
School	10	57.7	12.0	14	52.3	10.8	51	52.8	9.8	0.359

***F-test.

Two-groups testing for Physical Well-Being:

No parents vs One parent: p-value = 0.041
No parents vs Two parents: p-value = 0.015
One parent vs Two parents: p-value = 0.950

Table 5. HRQoL in paediatric IBD across the French and German part of Switzerland

	IBD Patients				
	Nb	Mean	Std dev.	t-value*	p-value*
German speaking					
Physical well-being	89	49.61	11.66	-0.319	0.750
Mental well-being	89	54.47	10.75	3.922	< 0.001
Parents/autonomy	89	55.61	10.98	4.826	< 0.001
Social support/peers	89	55.91	9.08	6.143	< 0.001
School	89	53.70	10.01	3.491	< 0.001
French speaking					
Physical well-being	21	40.10	10.01	-4.531	< 0.001
Mental well-being	21	48.82	9.44	-0.568	0.576
Parents/autonomy	21	49.39	13.43	-0.206	0.838
Social support/peers	19	49.78	15.04	-0.062	0.950
School	18	51.21	11.97	0.431	0.671

*Ho : mean = 50 (control)

	IBD Patients				
	Nb	Mean	Std dev.	t-value*	p-value*
German speaking – CD patients					
Physical well-being	50	49.60	11.75	-0.239	0.812
Mental well-being	50	54.56	10.48	3.073	0.004
Parents/autonomy	50	56.20	10.88	4.028	< 0.001
Social support/peers	50	55.64	9.49	4.207	< 0.001
School	50	55.04	10.83	3.294	0.002
German speaking – UC patients					
Physical well-being	39	49.60	11.69	-0.209	0.835
Mental well-being	39	54.36	11.23	2.426	0.020
Parents/autonomy	39	54.87	11.21	2.716	0.010
Social support/peers	39	56.26	8.64	4.522	< 0.001
School	39	51.99	8.70	1.427	0.162
French speaking – CD patients					

Physical well-being	14	38.96	10.14	-4.075	0.001
Mental well-being	14	46.03	8.73	-1.699	0.113
Parents/autonomy	14	49.76	13.88	-0.065	0.949
Social support/peers	13	48.89	15.47	-0.258	0.801
School	12	49.51	10.12	-0.169	0.869
French speaking – UC patients					
Physical well-being	7	42.39	10.11	-1.992	0.093
Mental well-being	7	54.41	8.83	1.322	0.234
Parents/autonomy	7	48.67	13.54	-0.260	0.804
Social support/peers	6	51.71	15.29	0.274	0.794
School	6	54.64	15.53	0.731	0.497

*Ho : mean = 50 (control)

Table 6. Age- and gender-specific HRQoL in paediatric IBD of the SIBDCS

	IBD Patients				
	Nb	Mean	Std dev.	t-value*	p-value*
Boys					
Physical well-being	62	46.79	10.74	-2.353	0.022
Mental well-being	62	52.31	10.55	1.727	0.089
Parents/autonomy	62	53.30	10.95	2.371	0.021
Social support/peers	60	53.29	10.07	2.529	0.014
School	60	51.68	9.70	1.339	0.186
Girls					
Physical well-being	48	47.75	12.64	-1.232	0.224
Mental well-being	48	53.20	10.52	2.107	0.041
Parents/autonomy	48	54.36	11.77	2.566	0.014
Social support/peers	48	55.97	10.69	3.872	< 0.001
School	47	52.80	9.73	1.970	0.055

*Ho: mean = 50 (control)

	Boys			Girls			
	Nb	Mean	Std Dev.	Nb	Mean	Std Dev.	p-value**
Total cohort							
Physical well-being	62	46.79	10.74	48	47.75	12.64	0.668
Mental well-being	62	52.31	10.55	48	53.20	10.52	0.663
Parents/autonomy	62	53.30	10.95	48	54.36	11.77	0.626
Social support/peers	60	53.29	10.07	48	55.97	10.69	0.183
School	60	51.68	9.70	47	52.80	9.73	0.555
CD Patients							
Physical well-being	41	46.66	11.40	23	45.58	11.86	0.722
Mental well-being	41	51.39	10.67	23	52.24	9.41	0.743
Parents/autonomy	41	52.26	10.22	23	56.50	11.72	0.154
Social support/peers	40	52.51	10.71	23	55.96	11.17	0.238
School	40	50.99	9.42	22	55.07	10.61	0.139
UC Patients							

Physical well-being	21	47.05	9.56	25	49.74	13.25	0.441
Mental well-being	21	54.11	10.33	25	54.07	11.57	0.992
Parents/autonomy	21	55.33	12.26	25	52.40	11.70	0.413
Social support/peers	20	54.84	8.70	25	55.99	10.45	0.689
School	20	53.04	10.34	25	50.79	8.60	0.441

**Two-sided

Figure legends

Fig.1: Mean scores and 95% confidence intervals according to gender. The red horizontal line represents controls score.

Fig.2: Mean scores and 95% confidence intervals according to age category. The red horizontal line represents controls score.

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